

Written Testimony of
Mary E. Kenney
Parent of a child with epilepsy
Friday, March 16, 2012
Public Health Committee

Raised Bill No. 369 - An Act concerning authorization for the use of feeding tubes and anti-epileptic medications in school settings.

Good morning Senator Gerratana, Representative Ritter, Senator Welch, Representative Perillo, and members of the Public Health Committee. Thank you for the chance to speak in support of this important Bill.

My name is Mary Kenney and I live in Cheshire. I am the mother of a fourteen (14) year old son, Patrick, who has epilepsy. My son started having seizures when he was 4 weeks old and since then, our family has ridden on a "roller coaster" of ups and downs. Over the past couple of years, he has been more stable but when he was younger, he was in **Status Epilepticus** almost every day. **Status Epilepticus** is defined as a dangerous condition whereas tonic-clonic seizures last more than 30 minutes or recur in a series of three or more seizures without the person returning to normal state in between. Patrick would have seizure after seizure (clusters) which frightened our family. My other children were afraid their brother would die and it was possible he could have. Initially when he started having these clusters, we would call 911 and then **wait**. The longest 5-10 minutes of my life! Once we started using the diazepam rectal gel (which is marketed as Diastat AcuDial), for Patrick's seizure clusters, we felt we could stop or slow them down so much faster. An added bonus was we didn't have to call 911 and instead would call his doctor after the seizure ended. We were also able to save on our medical costs by not calling 911.

Throughout our ordeal, we have relied heavily on medication to slow or stop our son's seizures. When you have a child with epilepsy, you really don't have a lot of control over the situation. You don't have control over when a seizure will start or stop; you don't have control during the seizure; you don't have control over the results of a seizure-mentally, physically or emotionally. We **do** have control over the medication we can administer to our children. Medication should be accessible throughout a child's day inside and outside of their home.

I strongly urge you to pass this Bill because I feel anti-epileptic medication should be available and administered throughout a student's school setting. Please ensure that the definition of a **school setting** includes not only the time the student receives instruction, but also the time during which the student otherwise participates in activities under the auspices of the local educational agency, such as being transported to and from school, field trips, extracurricular and co-curricular activities, before or after school programs, and camps or other activities that typically involve at least one overnight stay away from home. I have attached suggested language for your review. Trained non-medical personnel should be allowed to administer emergency medication assistance to students with epilepsy suffering from seizures, when a school nurse is not available.

Thank you again for giving me the chance to tell you my family's story and my support of this Bill.

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Suggested Language for **School Setting**

May include not only the time the student receives instruction, but also the time during which the student otherwise participates in activities under the auspices of the local educational agency, such as being transported to and from school, field trips, extracurricular and co-curricular activities, before or after school programs, and camps or other activities that typically involve at least one overnight stay away from home.